Human-centred design process when users have an evolving profile: a case study in Parkinson's disease domain

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Abstract. The human-computer interaction community has largely defended the use of an iterative process in which the users and stakeholders participate in all activities throughout the development of an interactive system. This work can become challenging when users have an evolving profiles in degenerative diseases (e.g. Parkinson's and Alzheimer's). The needs of the users at the start of the process may no longer be the same at the end when the system is validated. As consequence, it is important to integrate users in different stages of the disease in the whole process. The involvement of stakeholders (such as healthcare professionals, family members and caregivers) is also crucial for the better understanding of the user's needs and their evolving profile. This article presents how we deal with the evolving user profile in the development of a communication aid software for people with Parkinson's disease. To that end, we have customized the ISO 9241-210 human-centred process with a series of human-computer studies from a broad to a more focused goal. It presents this process and the complementary studies carried out with 97 people with Parkinson's disease, 5 relatives/caregivers and 5 health professionals. In light of the insights gained from this experience, we have formulated several recommendations for human-centred design in the context of a user with an

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ACM 2573-0142/2025/6-ARTEICS019
https://doi.org/10.1145/3735500

evolving profile. These recommendations outline a human-centred approach to guide the development of software applications for users with evolving profiles.

CCS Concepts: • **Software and its engineering → Software design engineering**; • **Human-centered computing → User studies**.

Additional Key Words and Phrases: human-centred design, user-centred design, empirical studies, evolving user profile, people with Parkinson's disease

ACM Reference Format:
Kathia M Oliveira, Christophe Kolski, Sophie Lepreux, Julia Greenfield, Véronique Delcroix, Yohan Guerrier, Elise Batselé, Taisa Guidini Gonçalves, Philippe Pudlo, Romina Rinaldi, and Anne Blanchard-Dauphin. 2025. Human-centred design process when users have an evolving profile: a case study in Parkinson's disease domain. *Proc. ACM Hum.-Comput. Interact.* 9, 4, Article EICS019 (June 2025), 34 pages. https://doi.org/10.1145/3735500

1 INTRODUCTION

User-centred design has been used in information technology since the 1980s/1990s, arguing that placing the user at the centre of system design, considering usability issues, is fundamental to the success of a project [56, 66]. In 1999, ISO calls this process human-centred design[1], to emphasize the importance of considering various stakeholders in the process and not just typical users [38]. Much work has been developed for different application domains considering different user profiles, such as children [46, 80, 83], the elderly [27, 39, 77] or people with disabilities [10, 12, 30, 31, 79]. We argue that applying this approach is necessary, yet not trivial while dealing with users with an evolving profile.

A profile is considered as evolving when certain characteristics of the user evolve progressively or abruptly over time in a degenerative manner (for example, progressive loss of movement/voice for people with Parkinson's, or memory for people with Alzheimer's). In this case, it is important to continue identifying the user needs throughout different stages of the disease in order to provide the right software for the desired purpose. We faced this situation when working on the European project named ParkinsonCom[2] [21], which aimed to develop a communication aid software for People with Parkinson's disease (PwP) in order to improve their social participation and inclusion. At the beginning of the project several questions emerged, such as: What are the communication needs of a person with Parkinson's disease? What are their difficulties? What is the adequate kind of interaction (e.g.: gestures, vocal, touchscreen)? What is the adequate human-computer interaction to provide? These questions are very common in any kind of system and particularly important to be well-addressed when the users are people with disabilities. Moreover, in this context, we had to deal with the degenerative character of the disease, and consequently the degeneration of the ability to communicate. This meant that we had to understand the different communication needs at each moment of the disease and that this would probably imply different technological support for communication. In summary, our primary research question is as follows: How can we design an interactive system for people with an evolving profile?.

In order to respond to the this research question, we advocate two key points. First, all stakeholders (users, medical professionals, caregivers, etc.) should be included in the core of the design process. This means that a human-centred design should be considered. Second, it is imperative to address each level of the evolving profile in a manner that aligns with its specific needs. Based on these assumptions, the goal of this work is to customize the ISO 9241-210 [38] standard for the development of the aforementioned interactive system for Parkinson's disease domain. All the activities in this process are described taking into account the particularities of dealing with

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[1] *human-centred design processes for interactive systems* in the withdrawn ISO 13407 standard revised by [38].

[2] https://parkinsoncom.eu

Parkinson's evolving profile integrating several human-computer studies. Based on the lessons learned from this experience, we have taken a step forward, proposing a generic process for dealing with the development of interactive systems when the user has an evolving profile.

The contribution of this article is twofold:

i. the definition and application of a human-centred design process for the development of a communication aid software for people with Parkinson's disease; and,
ii. the proposal of a human-centred design process to be used when users have evolving profile. This process specifies all the activities to be carried out for the development of interactive systems taking into account the evolving user profile and the participation of the different stakeholders involved in the process.

This paper is further composed of four sections. Section 2 describes the study background, briefly introducing the user profile of PwP and presenting the related work on human-centred design studies. Section 3 presents the customization of the human-centred design process adapted from ISO 9241-210 [38] for the development of a communication tool for people with Parkinson's disease. Section 4 summarises our lessons learned in carrying out this process over almost three years and proposes a first version of a generic human-design process to be applied when users have an evolving profile. Section 5 presents our conclusions and future work prospects.

2 BACKGROUND

2.1 Evolving User Profile in Human-Computer Interaction

In the design of an interactive system, two principles complement each other. On the one hand, user-centered design approaches which are necessary to properly take into account the needs and capabilities of users in order to offer usable interactive systems and a good user experience. This research work resulted, among others, in ISO 9241-210 [38] standard. On the other hand, adaptive system design approaches, introduced in the 1990s, focused on transfers of interaction between platforms [64] to the point of integrating a whole set of adaptations. Calvary et al. [17] propose the adaptation of the human–computer interfaces to their context of use, seen as a triplet: <user, platform, environment> ; the user is the part which is the focus in that article. In order to integrate the user, the notion of profile was therefore put in place [24, 47, 53], and regularly enriched to cover increasingly broad profiles and particular characteristics such as user personality [3]. Other approaches use user models [2, 26] in order to propose more intelligent and more complete adaptations.

However, human beings evolve during the use of the system. The evolution may be in terms of competence in the use of the system, as illustrated in a groupware context [14]. The evolution can also concern the needs in terms of progression in professional skills. In the fields of education [59, 60] or games [13, 74], we will find for example level systems to evaluate this and propose coherent activities with the progress of the learner, resp. of the player. The user profile can also change over the course of their life when a deficiency or an illness occurs (e.g. [32, 71, 72]). The developments can be in the direction of a regression which forces the user interface to take into account the associated deficiencies. If the impairment is permanent, the principles of inclusion and accessibility are adapted, but if the impairment is fluctuating, this is no longer sufficient. It is in this context that this research, aimed at integrating this profile evolution into the design of interactive systems, is located. However, we have not found any work in the literature targeting this consideration of the evolving profile in the development process.

2.2 The Evolving Profile of People with Parkinson's Disease

Parkinson's disease (PD) is a progressive, multi-system neurodegenerative disease that mainly affects older people. It has been identified as the second most common neurodegenerative disease worldwide, after Alzheimer's disease [68]. This disease is characterised by the destruction of a specific population of neurons, namely the dopamine neurons, and a subsequent disruption of dopaminergic neurotransmission in the basal ganglia [62]. These neurons are involved in the control of body movements, the loss of which is the most characteristic motor symptom of this disease.

Among the motor symptoms, bradykinesia is noted in all cases, i.e., a slowness in the initiation of voluntary movements with a progressive reduction in the speed and amplitude of repetitive actions (hypokinesia). Bradykinesia is always accompanied by at least one additional motor symptom, such as muscular rigidity or rest tremor [68]. Motor symptoms have long been the focus of disease management although non-motor symptoms are often reported to be more bothersome for patients [61]. Non-motor symptoms are classified as: dysautonomic signs (such as, digestive disorders, swallowing problems, arterial hypotension, respiratory disorders), sensory disorders (pain), speech disorders and psychological and cognitive disorders (sleep disorders, memory disorders, fatigue, depression, anxiety, and apathy) [61].

As the disease progresses, there may be alternating periods in which the symptoms are largely under control thanks to treatment, and periods in which the treatment no longer has a sufficient effect. This is commonly called as an alternation between *ON* period, when the treatment is effective, and *OFF* period, when the treatment has no effect [76].

Several scales are used to diagnose Parkinson's disease and its stage. These include the UPDRS (Unified Parkinson Disease Rating Scale) [58], the Hoehn and Yahr scale [32], and the Parkinson's Well-Being Map™ [71]. The UPDRS is a widely applied rating instrument for PD composed of several items contributing to three subscales: (a) mentation, behavior, and mood; (b) activities of daily living; and (c) motor examination. The Hoehn and Yahr scale has also been used for the staging of the functional disability associated with Parkinson's disease. It helps to describe the progression of the disease through various stages, thus allowing to measure the severity of the case. Assessment with both scales requires a medical examination and the history given by the patients and their caregivers. The Parkinson's Well-Being Map™ has been designed by physicians and patients to make it easy for the patients themselves to describe their difficulties and highlight the most burdening symptoms in order to guide their care. The items, organised in different categories (Figure 1), are sentences that should be answered using a 5-point Likert scale (from 0-never to 4-always).

2.3 Human-centred Design in case of Users with Parkinson's Disease

Human-centred design, or user-centred design, is defined by ISO 9241-210 [38] as "an approach to interactive system development that aims to make systems usable and useful by focusing on users, their needs and requirements, and by applying human factors/ ergonomics, and usability knowledge and techniques". Although the terms user-centred and human-centred are often used synonymously [38], we prefer to use the term human-centred in this work because the participation of stakeholders directly related to the user with an evolving profile in the development of the application, is often necessary, as also defended by [30] for the design of interactive systems for people with disability, particularly in case of communication disorders.

The basis of this approach is that stakeholders and users are involved in the design, development and evaluation of the interactive system in a iterative process until the desired result, in a degree of usability, is achieved. Involvement during development enables user and task requirements to be identified and incorporated into the system specifications. This involvement also enables feedback

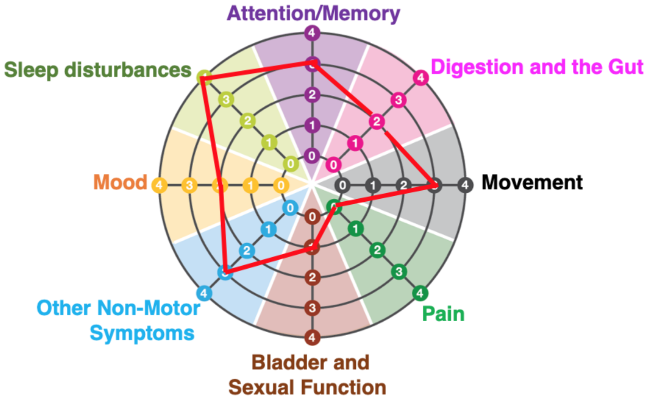

Fig. 1. Categories of Well-Being Map™ with the result of a self-assessment (red line)

to be obtained by testing the proposed design solutions. Indeed, users' participation is a source of knowledge about the context of use and the way in which they are likely to use the product. The context of use encompasses information about users, goals and tasks, resources, and environment (including the technical, physical, social, cultural and organizational environments) [37].

Human-centred design has been applied in different work on Parkinson's disease for different purposes. We can quote, for instance, for the detection of PD (e.g. [25, 44, 69, 82]); for self-monitoring, self-treatment or self-care of PwP (e.g.[20, 43, 72, 73]); for daily treatment monitoring (e.g. [40]), and for understanding communication disorders (e.g. [6, 50]), sleep and anxiety disorders (e.g. [22]), sleepiness, depressive mood, hallucination and psychosis (e.g. [23]). All these studies were focused on the disease in general considering diagnosis and monitoring and not taking into account the different stages or evolution of the disease or specifically of one of the aspects of the disease.

In terms of techniques, interviews [15, 57, 73, 82], workshops [49, 82], questionnaires [6, 15, 20, 43, 49, 50, 52, 73] and focus groups [20, 41] are usually applied in the user-centred process.

In previous work [29], we have carried out a rapid review [70] on human-centred design approaches for the development of communication software systems. In our research in Scopus (01/09/2020) with the search string ((”user-centred” OR ”human-centred” OR ”user-centered” OR ”human-centered”) AND (”communication” OR ”conversation” OR ”ICT” AND ”Parkinson”), no results were found. So we decided to use ”OR Parkinson”, to find studies on human-centred design for communication in any domain or the application of human-centred design for the Parkinson's domain. We excluded studies on robots. By doing the searching in Scopus followed with snowballing procedures, we found 15 works (e.g. [5, 20, 35, 48, 50, 51, 57, 75]) on the Parkinson's domain and 52 works on other domains such as: autistic spectrum disorder (e.g. [1, 18, 36, 80, 83]), cerebral palsy (e.g. [34]), elderly (e.g. [9, 27, 42, 77]), and intellectual disability (e.g. [19, 79]). None of the 15 papers on Parkinson's domain mentioned the use of the human-centred design standard (ISO9241-210 [38]) and only 5 of the 52 on the other domains cited its use or the previous version. Of these 5 articles, one [63] cites ISO 9241-210 only to clarify the definitions of usability, two others [1, 54] use the standard process detailing its activities in various phases, another [33] defines a three-phase process based on the standard's activities, and the last one [78] specifies the process for integrating stakeholders into the general process, but does not change the way the target user is taken into account in the process. Furthermore, no work in this review took into account the evolving profile issues in their propositions. The studies always focus on a specific functionality considering the disability in general and not considering the evolution of the profile. Although this review was carried out in 09/2020 (when we started this research) and we have continued to work in this field and others related to people with special needs, as far as we know, this result is still valid, i.e., there is no work that takes into account the issues of the evolving profile in the design of interactive systems.

3 DESIGN AND IMPLEMENTATION OF AN INTERACTIVE SYSTEM FOR PEOPLE WITH PARKINSON'S DISEASE

As previously mentioned, we were confronted with the difficulty of dealing with a evolving user profile in the context of a project for Parkinson's disease domain. This Interreg France-Wallonie-Vlaanderen project was carried out between April 2020 and December 2022 [21]. The goal of this project was to develop a software aid to support PwP to communicate with their entourage. This project was conducted by two universities and a medium-sized enterprise. Moreover, two hospitals (Lille University Hospital Center, France and UZ Brussels Hospital, Belgium) and three Parkinson's Associations (FranceParkinson Nord in France; Vlaamse Parkinson Liga and APK Parkinson Association a.b.l. in Belgium) participated as collaborators.

To address the development of this software systems, we decided to work in the adaptation of the human-centred process of ISO 9241-210 standard [38] considering not only the users, but all other stakeholders involved in the problem. This adaptation was deemed necessary, as the standard process involves the identification of a set of user needs and subsequent iterative development with those needs as a focal point. In our particular case, we were confronted with a degenerative user profile, and it became evident that the communication requirements could vary significantly between stages of the Parkinson's disease. In essence, it was recognized that each stage of the disease's progression entailed the emergence of a novel user profile, characterised by distinct requirements. In essence, the process delineated in the ISO 9241-210 standard is being executed in its entirety for each identified level. After the identification of the various levels, the process is executed in multiple instances concurrently. The outcomes of these instances are then integrated into a unified system. Figure 2 presents this idea by the overlap of the three main activities of the process. We have decided that in the first activity we should carry out studies to identify the different levels of communication for Parkinson's disease we should have to address.

Moreover, we decide to integrate the main principle of participatory research [11] and participatory design [67] which advocates the active participation of the stakeholders in the process. The idea was to use the same activities as the standard, enriched with various human-centred studies, ranging from a *broad* to a *precise* vision for development and evaluation. For a broad vision, comprehensive studies should be carried out seeking to collect results from a significant number of users, thereby facilitating a general understanding of the problem. This can be achieved through the use of internet surveys, which provide a more extensive data set. This can be followed by in-depth interviews, which will facilitate the generation of more focused insights into a more precise understanding of the problem. Each activity was reviewed considering the perspective of developing an interactive system for users with an evolving profile, as described in the sub-sections presented bellow.

The activities presented in green in Figure 2 represents the execution of the evolving profile level that we will be present in detail in the next sub-sections, with particular attention paid to the integration of the evolving profile issues.

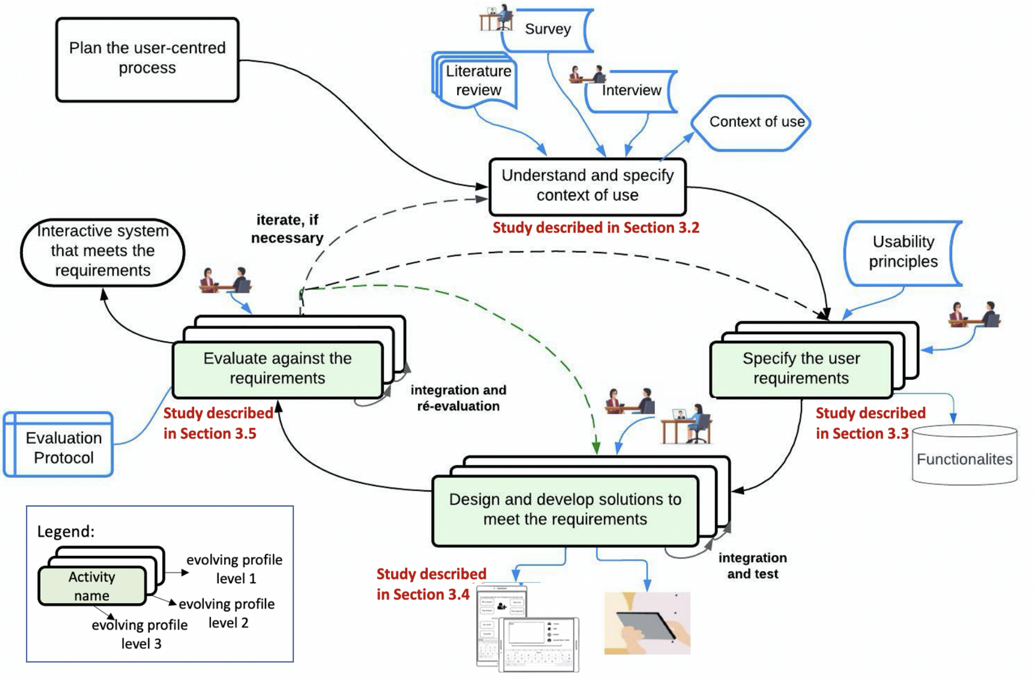

Fig. 2. Human-centred design of an interactive system for PwP

3.1 Plan the Human-centred Process

As proposed in the ISO 9241-210 standard, we started the project planning the human-centred process for our project. In this activity we should describe the activities to be performed, the material and human resources, cost and time constraints.

Regarding human resources, besides the technical team, we identified the following stakeholders to participate in the process: a physician expert in Parkinson's disease, two neurologists, two speech therapists, and several caregivers from the Parkinson's associations. Moreover, the Parkinson's associations agreed to invite the PwP from the associations to participate in the project. In terms of material, at the beginning of the project we did not know what kind of technology could be adapted to PwP.

In order to have participatory research and design, we planned several studies from a broader perspective to a more precise one. We started (Section 3.2) with an initial interview with a physician and speech therapist and a general survey (Section 3.2.1) on PwP's difficulties and communication needs. Then we carried out interviews (Section 3.2.2) to better identify their needs and the different levels of the communication difficulties. Other interviews were also carried out for the requirements specification (Section 3.3) and to define the user interface design elements (Section 3.4) for the software application. Finally, after developing the application we planned evaluation sessions with PwP (Section 3.5). Threats to validity on these studies were duly analysed (Section 3.6).

We came up against two important restrictions in our project: the end of the project set to December 2022 (no extension would be accepted) and the COVID-19 pandemic which lasted from the start of the project in April 2020 until mid-2021 when the vaccines began to be used. This last restriction limited the interviews to video conference meetings and made it impossible to carry out participatory design for the conception of the user interfaces or the use of focus groups.

3.2 Understand and Specify Context of Use

This activity was started by a literature review on PD, regarding symptoms, communication difficulties and treatments (the result of this literature review is presented in the background section, see Section 2.2).

With this study in mind, a first interview by video-conference with the physician expert in PD and a speech therapist took place. The interview was guided following five general questions:

i. Given that Parkinson's disease is progressive, would it be possible to define which patient profile(s) we should focus on for the development of the communication aid software system?
ii. What do you think would be interesting for PwP in terms of communication?
iii. What kind of interaction with computers would be possible for PwP? Do you think we can combine the use of voice with touch (touching a screen, for example) and gesture (a specific movement) for communication?
iv. What type of technological device do you think we could use for the software for this type of patient (e.g. cell phone, large-screen tablet, devices that can be worn by the patient as an ear kit, glasses with data display/augmented reality, etc.)?
v. Do you know whether some patients are used to working with communication aids (if so, which ones)?

The interview took 45 minutes. Concerning the first question (i), they considered we should focus on people with oral communication problems, intelligibility problems and communication difficulties, if possible without cognitive impairment (no cognitive impairment, no cerebellar syndrome). This should be based on the difficulties encountered in daily life, where the disorders cause difficulty. The physician mentioned that the evolution of Parkinson's disease is mainly in terms of cognitive disorders. Also that assessments of articulation, speech capability and intensity are usually performed by speech therapists using specific tools and it is very difficult to do this assessment using software tools.

With respect to question (ii) they mentioned that PwP are moderately motivated. Thus, it is necessary to have something practical, easy to use and appropriate. According to the experts, if it is too elaborate, too difficult, PwP will not use it. "It has to be simple, intuitive and adaptive", mentioned the physician expert in PD.

On the kind of users' interaction (iii) they emphasized that PwP can point with their finger. But that oral communication tools are too long and difficult to use and that the use of gestures is not possible because PwP often have involuntary movements. They emphasized that any type of interaction that implies an immersive environment is not appropriate for PwP because it is too disturbing.

Regarding the potential technological devices (iv), they recall that most of the patients are elderly, over 60. Therefore, all advanced technologies (glasses, ear kit, virtual environment, etc.) are not possible for them. They suggest the use of tablet, half the size of an A4 page, with a virtual keyboard on one part of the screen and pictograms on the other (we represent that in Figure 2 including a picture of a tablet). They suggested also the use of different coloured vowels to make them easier to identify, and other elements of this kind to make it easier to use.

Finally, concerning the use of communication tools (v) they said that, in general, a small number of PwP have already worked with pictograms and alphabet books, but this is rare.

After this initial interview, a questionnaire for a survey was elaborated and reviewed by this physician. The details of this survey are presented in Section 3.2.1. To better understand the needs and identify the different levels of the evolving profile for PwP regarding communication, several interviews were carried out, as presented in Section 3.2.2.

3.2.1 A Survey for Knowing PwP's User Profile and Needs. This survey was designed to better understand the PwP's particularities, by identifying the different characteristics of PwP, their different needs, and their experience with technological support (computers, mobile phones, tablets, mouse, etc.). Our aim was to get as broad a view as possible, encompassing a large number of potential future users (PwP). For this reason, an online survey seemed appropriate as it provided a time-efficient way to collect data from a larger study sample and was feasible at the given time period with relevant restrictions (COVID-19 pandemic).

The research protocol for the investigation of PwP's user profile and needs covering a survey and interviews (presented in the next section) was approved by the ethical committee of the Faculty of Psychology and Educational Sciences [3], University of Mons, Belgium.

Goal. To obtain an overview of the difficulties experienced in PD and the associated communication problems from the point of view of PwP and their relatives/caregivers. More specifically, our interest was to identify (i) the impact of PD on the daily lives of PwP, (ii) their communication difficulties, (iii) the strategies they use to communicate with their surroundings, and (iv) their needs in terms of social communication in everyday life. Moreover, in order to better define the type of technological device to use, we also looked to identify (v) known and used technological devices.

Participants. PwP and relatives representing a PwP. Our inclusion criteria therefore relate to the fact of being diagnosed as having developed PD or of being the close carer of a PwP. Specifically, we considered the response to questionnaires from PwP. The recruitment method was based on voluntary participation following the dissemination of information via the Internet and social networks.

Methods. A questionnaire was drawn up with identification information (age, gender, marital status, confirmation of diagnosis and approximate date of the diagnosis) and a set of closed questions to answer the five specific objectives defined: *(i) impact of PD symptoms on their life*, *(ii) communication difficulties*, *(iii) strategies used to aid communication*, *(iv) communication needs*, and *(v) the experience with technology devices.* Each of the closed questions also contained an open option (other) for free completion. The questionnaire was coded using LimeSurvey, taking precaution to guarantee the anonymity of the interviewees. The questionnaire was elaborated considering scientific literature and was reviewed by the physician specialised in PD previously interviewed.

Results. We received 56 complete responses to the questionnaires (35.71% from men (n=20) and 64.29% from women (n=36)). On average, respondents were 58 years old (standard deviation 11.9). Four early cases (less than 40 years old) were identified. We highlight the following results:

- With regard to the *(i) impact of PD symptoms* on their lives, the respondents were asked to answer on a 4-point Likert scale (no, minor, moderate or major -impact) the severity of 25 common symptoms. To analyse the answers we considered symptoms in two categories: physical (lower limb tremor, upper limb tremor, involuntary movements/dyskinesia, pain/cramps, pain in the joints of the upper limbs, pain in the joints of the lower limbs, slowness of movement, lack of precision in movement, difficulty initiating movement, difficulty walking, balance problems and/or falls, fatigue and/or sleep problems, and bowel and/or bladder problems) and psycho-social (sadness/negative thoughts/anxiety, hallucinations, feeling of loneliness, difficulty managing emotions, difficulty carrying out leisure activities, difficulty concentrating, memory problems, difficulty organising and planning activities, difficulty swallowing, difficulties with writing, difficulty communicating orally, and variations between *ON/OFF* periods). The three main physical symptoms with proven impacts (moderate or

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[3] No specific number was specified in the approval document dated 18/12/2020.

major impacts) are: fatigue and/or sleep problems (48.21%), pain/cramps (41.07%), slowness of movement (41.07%). The three main psycho-social symptoms with proven impacts (moderate or major impacts) are: difficulty concentrating (44.64%), difficulty writing (35.71%), difficulty communicating orally (33.93%).

- Concerning *(ii) communication difficulties*, they had to answer yes/no/"I don't know" to a list of 10 items (difficulty perceiving their own voice, communication-related fatigue, difficulty finding words, difficulty continuing a discussion, difficulty initiating a discussion, difficulty articulating, speech rate too slow or too fast, monotone voice, hoarse/harsh voice, and voice of low intensity). The three main difficulties most frequently encountered by respondents to the questionnaires were: voice of low intensity (71.43%), communication-related fatigue (60.71%), and difficulty finding words (58.93%).
- For the *(iii) strategies used to aid communication*, they should also answer yes/no/"I don't know" on a list of 11 items (avoiding difficult situations, waiting for a better moment to speak, shortening the information, speaking louder, preparing the talk in advance, informing others about the difficulties, speaking slower, asking for help, use of a communication software, use of pictograms/images, and writing instead of speaking). The strategies most frequently used by respondents to the questionnaires were (Figure 3): avoiding difficult situations (e.g. noisy, stressful) (80.36%), waiting for a better moment to speak (66.07%), and shortening the information, getting straight to the point (60.71%).
- Regarding the *(iv) communication needs*, the respondents were asked to rank situations (discussing a subject, making requests, expressing my feelings, exchanging ideas, giving an opinion, and telling a story) in order of importance for them. We scored the first classified event with six points and the last one with just one point. In this way, we obtained an average for the entire sample. The three main needs that emerged were: discussing a topic, making a request and expressing their feelings.
- Regarding *(v) the experience with technology devices*, the majority of respondents use computers (89.29%), smartphones (83.93%), tablets and touch screens (66.07%), for instant messaging (85.71%) and video conferencing systems (Messenger, Whatsapp, Skype, Viber, Duo, etc.) (85.71%). It is also noted that new interaction technologies such as virtual reality headset (7.14%), eyetracking (0%) and joysticks (3.57%) are indicated as mostly unused. This information is confirmed by medical experts in PD, who indicate that these technologies are not suitable for PwP.

Finally, in order to assess the impact of PD symptoms on respondents to the questionnaires with regard to the stage of the disease, an average was calculated based on the question related to the impact of PD symptoms on their daily lives, using the score attributed by each participant for physical and psychosocial symptoms, and communication difficulties. A correlation analysis showed no relationship between the stage of the disease (years since diagnosis) and the impact of physical symptoms (r= p.14, p= .29), psychosocial symptoms (r= .07, p=.60), and communication difficulties (r= .20, p= .13) meaning there is not a "typical" profile of linear evolution of symptoms with the stage of the disease being more advanced. Figure 4 visually confirms that the symptom impact varies between participants and that PwP having a more advanced disease do not always exhibit the most problematic symptoms/difficulties. The same correlation analysis was carried out with age and was found not significant for physical symptoms (r= .05, p= .68), psychosocial symptoms (r= .04, p= .74) and communication difficulties (r= -.03, p= .84) (see Figure 5).

These results confirmed that the communication is truly a difficulty for every PwP. To manage this difficulty, PwP tend to avoid situations requiring communication, but this is not always possible considering that communication is necessary for making simple requests or expressing feelings.

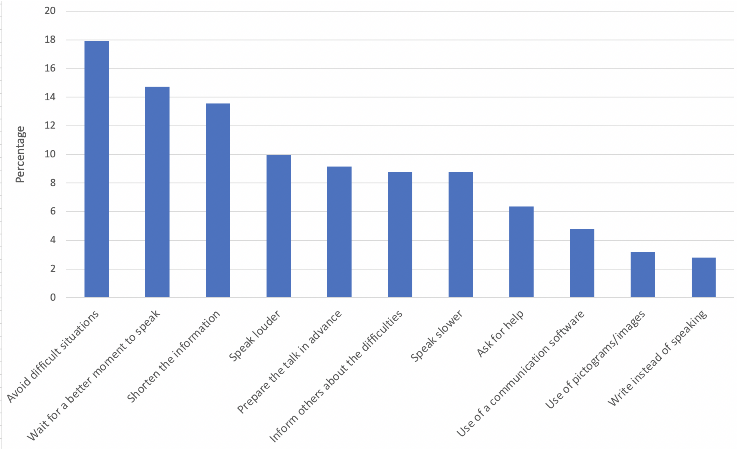


Fig. 3. Communication strategies used by PwP

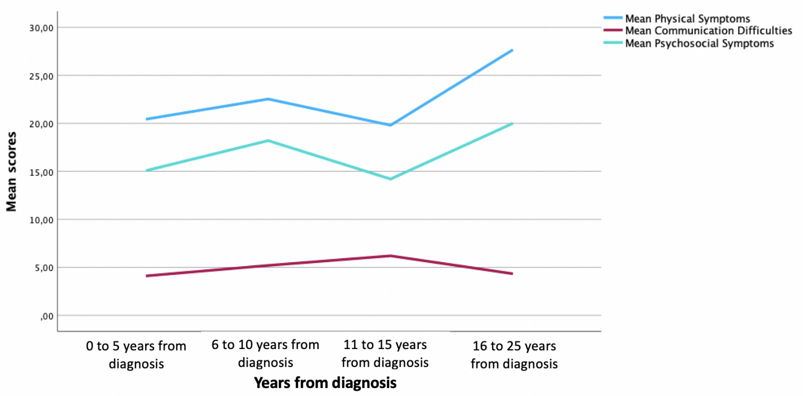


Fig. 4. Correlation analysis between the stage of the disease (years since diagnosis) and the impact of symptoms

Other compensatory strategies are also often used by the participants such as waiting for a better moment to speak or shortening the information to be communicated. In a smaller proportion, some PwP also indicated that they use communication software or pictograms/images or writing to help them to communicate (see Figure 3).

A correlation analysis highlighted that age is not linked with the use of technology (r= .10, p= .47) meaning that participants use technology as much at a young age as at an older one. The same was observed for the stage of the disease that showed no relationship with the use of technology (r= -.15, p= .26).

Thus, this study did not allow us to truly identify the different levels of the evolving profile to accurately target different communication support needs, as each PwP is affected differently. Indeed, the symptoms do not seem to be specifically influenced by the disease stage, or by age. Moreover, the use of technology is not directly linked with age reinforcing the idea that support

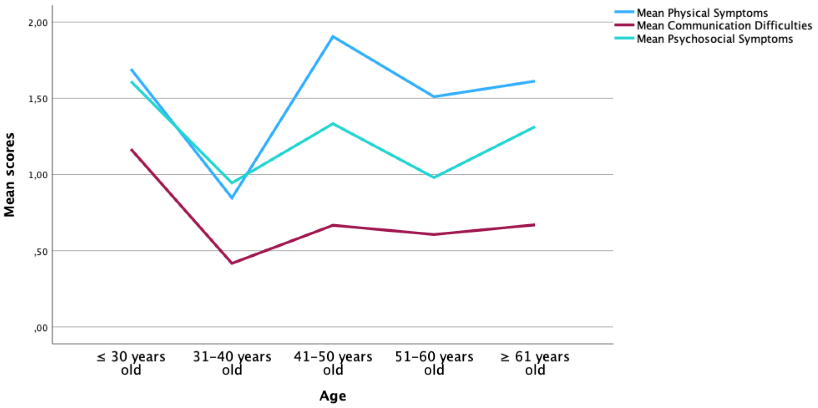


Fig. 5. Correlation analysis between age and the impact of symptoms

technology which targets communication could be a path to explore. We therefore decided to carry out interviews to delve deeper into these issues.

3.2.2 *Interviews for Defining Evolving Profile Levels and Context of Use.*

Goal. The interviews were planned with two main objectives: to better understand the physical and psycho-social impacts of the disease and their impact on communication (quantitatively identified in the survey presented in the previous section), and to define different levels for the evolving profile taking into account their communication difficulties.

Participants. PwP or relatives representing a PwP. The recruitment method was based on voluntary participation from members of the Parkinson's associations that collaborated with the project and by invitation disseminated on the Internet and social networks. The relatives were interviewed in case where the PwP could not express themselves orally. They were asked to answer considering the PwP persona as much as possible.

Methods. An interview guide was established starting with identification information (age, gender, marital status, confirmation of diagnosis and approximate date of diagnosis). Next, a set of questions covering the following topics was carried out: the interviewee's life journey (feelings about the disease and the diagnosis, daily activities and changes in activities/habits); the impact of PD on the interviewee's life from a motor and non-motor point of view; the difficulties and strategies used to communicate with the people around them; the interviewee's relationship with technology, and in particular their expectations regarding the creation of a technological tool to support communication. For anonymisation, each interviewee received a colour code.

Results. We carried out 14 interviews, corresponding to 10 men (71%) and 4 women (29%) with PD. Of these 14, 10 were carried out with the PwP and 4 with relatives (wife/husband), who act usually as caregivers, answering based on the day-to-day running of the PwP (three men and one woman). We note that the dates of diagnosis vary less than for respondents to the survey. For many, the diagnosis was made several years prior the interview date (average diagnosis received: 11 years and 10 months). The interviews took an average of one hour and were conducted by video-conference due to the COVID-19 pandemic. All interviews were transcribed and a qualitative analysis was performed related to the psycho-social perspective. This analysis can be found in [8].

In this paper, we focus on the needs of communication to define the different levels of the evolving profile. To that end we summarized the results of the interviews in the main elements collected in the interview, as shown in Table 1 for the interview of two PwP. Then, we summarized all communication needs (potential use for the system) that PwP would like to address in Table 2. We note that ”make a request” or ”communicate by text” are the most commonly cited communication needs.

The interviews confirmed what was observed in the survey, i.e., that PD symptoms are not directly related to the age or the number of years of diagnosis. However, by carrying out the interviews, we identified clearly that some participants communicate orally without problems (participants named Bordeaux, Red, Khaki and Cyan), some have some difficulty but can be understood (White, Pink, Black, Green, Beige), and some others with major difficulties or who are no longer able to speak, with the interview being conducted with their relatives (Brun, Gray, Violet and Ruby). For this last group, the need for assistance in ”making a simple request” was expressed, contrasting to those who can still communicate and asked for a support tool to ”find words in real time” while they are speaking.

Furthermore, all parties expressed that the *OFF* periods rendered them incapable of communicating effectively independent of the stage of the disease. They are aware that they simply need to wait for the *OFF* period to end.

A thorough analysis of the interviews revealed two distinct extremes in terms of the level of communication difficulty exhibited. On one end of the spectrum, participants demonstrated a capacity to articulate themselves with relative ease, exhibiting a near-normal level of verbal expression. On the other end, participants exhibited a complete absence of verbal communication (The interviews were conducted primarily with the relatives who were accompanying the PwP). Based on that, we have decided to use an ordinal scale to define the evolving profile level. This decision has been taken in light of the two extremes and a middle one. Consequently, three levels were delineated, as presented in Figure 6. Moreover, the scales for diagnosis of PD (see Section 2.2) usually have some items directly related to speaking ability. Even better, the Well-Being Map™ scale (presented earlier, see Section 2.2), that is used for self-assessment of PwP, presents an item directly related to this (”I have trouble talking”) and other items that can be associated to the problem of communication (e.g. ”I have difficulty remembering names, numbers, events”).

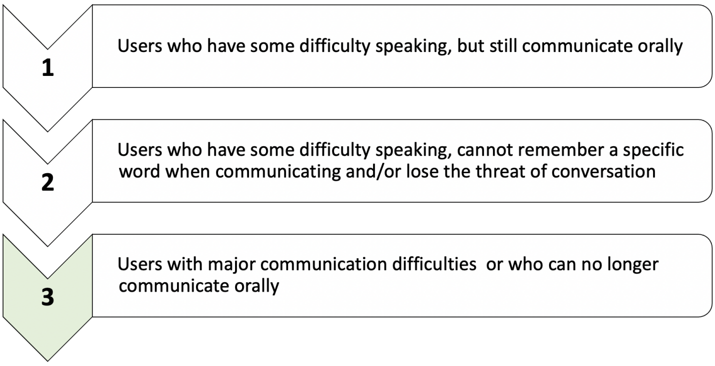


Fig. 6. Three levels of evolving profile for PwP related to communication (studies of level 3 are presented in this article)

Table 1. Example of summary of interview answers from two People with PD

Interview elements	Mr. Pink, 68 years old, PD since 2005	Mrs. Khaki, 61 years old, PD since 2016
Aspects of the disease	Sometimes his voice is dull, his diction cottony and he has difficulty finding his words. *ON/OFF* periods.	Good communication, but problems with reversing or forgetting words, slow thinking. No variations between *ON/OFF* periods.
Communic. needs	Help and encourage people to express themselves in real time.	Being able to talk to her husband and friends. Conversing, expressing herself in meetings.
Daily activities	Intellectual activity (writing a book), participation in several associations, corresponding with friends.	Frequent (sport, cultural activities, everyday activities, entertaining the family).
Moral	Good	Very good
Openness to technology	Wide open.	Moderate (good use of computer, smartphone. Owns a tablet, but does not use it).
Ideas for technology support	Tablet or smartphone. Search for a word (in real time if possible). News and contextualised information.	A tool to help communicate with others PwP. Encourage and correct writing.
People support	No	Mainly medical (neurologist every 6 months).
Strategies for communic.	When he gets into a discussion too quickly, he waits for a better moment.	Writing in preparation for meetings. Cutting off communication and wait for a favourable moment.

The interviews also revealed that future users would like a system mainly to be used in their own houses, to support daily life. They also mentioned that it could be interesting as support during medical visits. Therefore, two use environments should be taken into account as an element of the context of use: PwP's house and a doctor's office.

3.3 Specify the User Requirements

This activity was started by interviewing the physician expert in Parkinson's disease, the two neurologists, and a representative of the Parkinsons' associations. The goal was to present the results of the previous activity, the levels of PwP evolving profile defined for communication, and discuss potential solutions to the problem.

With the three levels identified and the list of needs, the interviewees scored which needs would be most relevant for each level. In addition, they acknowledged that user would not be able to use communication features during the *OFF* period independent of the evolving user profile level. However, some service that did not require a lot of interaction could be offered to help them wait

Table 2. Summary of the main needs

PwP colour code	Gender-Age	Make a request	Communicate by text (w/wo vocal synthesiser)	Find a word in real time	Networking (with PwP, doctors)	Increase voice volume	Know latest PD's news
Gray	W - 69	X	X				
Khaki	W - 61		X		X		
Blue	M - 60		X	X	X		
White	W - 67		X				X
Black	M - 48			X	X		
Bordeaux	M - 63						X
Violet	M - 75	X	X			X	
Pink	M - 68		X	X	X		X
Cyan	M - 71		X				
Red	M - 64				X		X
Beige	M - 49		X	X	X		
Ruby	M - 73		X		X		
Brun	M - 74	X	X				
Green	W - 69	X	X				

Table 3. Needs per evolving profile level

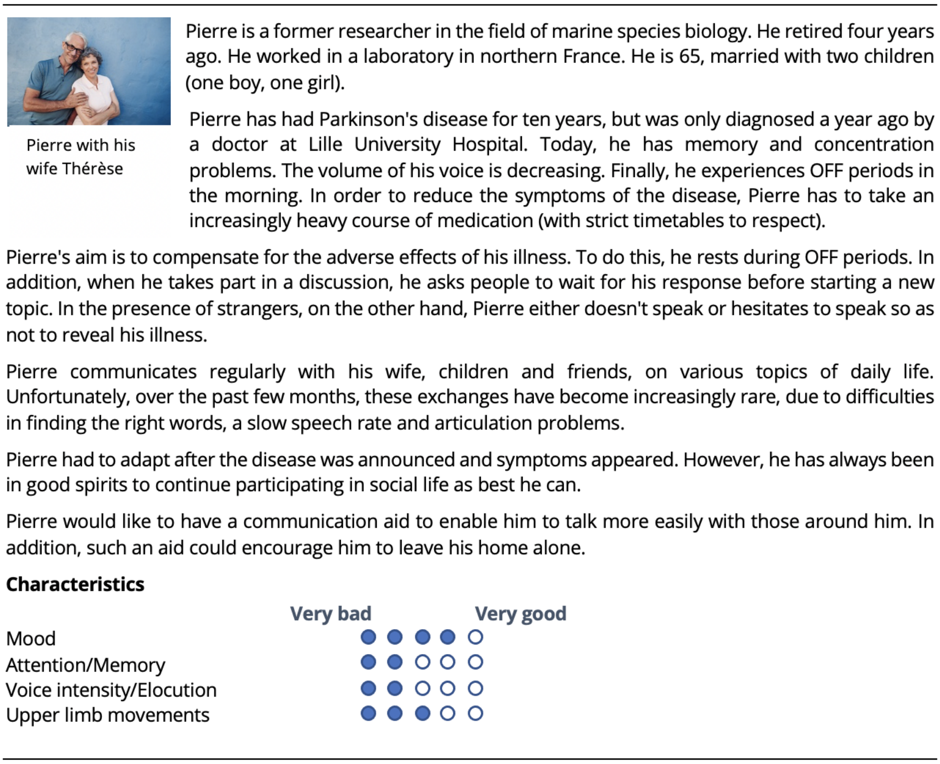
PwP needs	Level 1	Level 2	Level 3
Make a simple request			X
Communicate by text without synthesizer	X	X	X
Communicate by text with synthesizer			X
Find a word in real time		X	
Networking(with PwP, doctors, friends)	X	X	
Know latest news on the PD	X	X	
Relaxation (family photos, music, video)	X	X	X

for the end of the *OFF* period. To that end, somme relaxation functionalities were included. Table 3 presents the needs that will be applied for each level.

It is important to note that no conflicts were identified during the course of the interviews in the previous activity. This is most likely due to the narrow focus of the interviews, which was specifically on communication needs. Otherwise, it would be advisable to consider applying to other interviews in order to resolve any conflicts that may have arisen, as this may lead to the identification of new requirements.

During the interviews, the physicians also stated that the system should be adaptable to each user profile level. It was specified that, upon commencing the application, users should respond to a series of questions (based on Well-Being Map questionnaires) regarding their current level of difficulty in communicating. In line with the responses provided, the system will ascertain the user's current level and deliver only the designated functionalities appropriate to that level [4]. Furthermore, it was specified that the system could be adapted by the user, with a number of options available for personalisation.

We concluded that the specific needs of each profile should be specified in detail and the functionalities should be defined to develop a complete software to support communication for PwP. The system may be adapted for each level so that it can be used continuously when the profile evolves to the next level. The main result of this interview was to start the development focusing on profile level 3. With a small technical team, we could not work in parallel for the three levels as desired. Although they say that level 3 corresponds to the minority of PwP, it nonetheless represents those who truly need communicative support. The activities in green in Figure 2 represent this focus. The physicians also decided for the use of tablets as an appropriate technological device. We note that the results of the survey and interviews show that this device is well-known by PwP. Moreover, we decided to use the Android platform to develop a free software application.



Pierre is a former researcher in the field of marine species biology. He retired four years ago. He worked in a laboratory in northern France. He is 65, married with two children (one boy, one girl).

Pierre with his wife Thérèse

Pierre has had Parkinson's disease for ten years, but was only diagnosed a year ago by a doctor at Lille University Hospital. Today, he has memory and concentration problems. The volume of his voice is decreasing. Finally, he experiences OFF periods in the morning. In order to reduce the symptoms of the disease, Pierre has to take an increasingly heavy course of medication (with strict timetables to respect).

Pierre's aim is to compensate for the adverse effects of his illness. To do this, he rests during OFF periods. In addition, when he takes part in a discussion, he asks people to wait for his response before starting a new topic. In the presence of strangers, on the other hand, Pierre either doesn't speak or hesitates to speak so as not to reveal his illness.

Pierre communicates regularly with his wife, children and friends, on various topics of daily life. Unfortunately, over the past few months, these exchanges have become increasingly rare, due to difficulties in finding the right words, a slow speech rate and articulation problems.

Pierre had to adapt after the disease was announced and symptoms appeared. However, he has always been in good spirits to continue participating in social life as best he can.

Pierre would like to have a communication aid to enable him to talk more easily with those around him. In addition, such an aid could encourage him to leave his home alone.

Characteristics

	Very bad				Very good
Mood	●	●	●	●	○
Attention/Memory	●	●	○	○	○
Voice intensity/Elocution	●	●	○	○	○
Upper limb movements	●	●	●	○	○

Fig. 7. Simplified example of a defined persona

The specification of the user requirements was performed by applying known techniques. Four personas [55] were defined based on the interviews previously carried out (see a simplified example

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[4] This has not yet been implemented, since we have only implemented one level of the evolving profile so far.

in Fig. 7, helping the software designers to keep in mind throughout the software process. We also described the functionalities with an use case diagram and a task analysis model [16].

3.4 Design and develop solutions to meet the requirements

This activity consisted of the design of the user interface and code of the software application. It ‘started with the development of several mock-ups considering the task models elaborated in the activity *Specify the user requirements*. Co-design is usually recommended in a user-centred design approach to define the user interface layout. Thus, two design workshops were organized with psychologists, psycho-educators, HCI specialists and an expert in communication tools for people with disabilities. These allowed a number of suggestions to be made regarding the functioning and presentation of the system. To that end, we developed different mock-ups for each defined functionality, and carried out other interviews by video-conference in order to validate and define some interactive design options as follows:

- button placement (horizontally aligned at the top or vertically on the side);
- the positioning of the interfaces on the tablet (landscape or portrait);
- the way suggestions are presented to complete the text (text only, pictogram only or pictogram and text);
- the type of keyboard (classic Android keyboard or Swiftkey, commonly used on Android platforms, known for its text prediction quality [4]); and,
- the choice of a symbol for the identification that they are in *OFF* period (thumb down, smile, sad or text).

In addition, we sought to identify whether the chosen features would meet expectations and suggestions for prototype development. Those features concerns to support make a request, communicate with and without vocal synthesiser and relaxation options.

Figure 8 presents three mock-ups about the choice to support text completion with (1) only pictograms, (2) only the text to be completed and, (3) pictograms with text. To that end the PwP interviewed previously were invited to give their opinion and feedback.

A detailed description of the design of the mock-ups and evaluation with PwP can be found in [28]. This user-centred study can be summarized as described below.

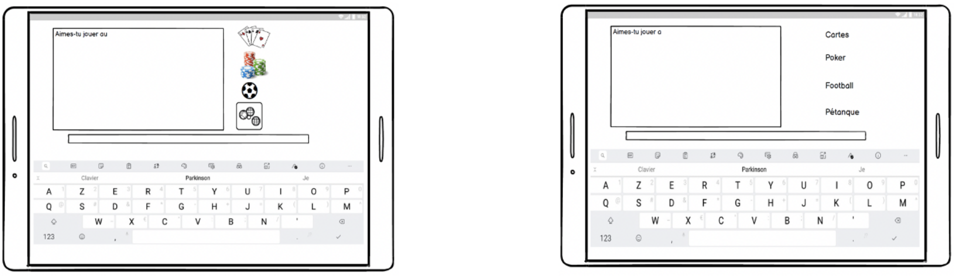
Goal. To decide on interactive design elements related to the user interface and validate the feature that would be implemented.

Participants. Invitation of PwP previously interviewed and contacts from the Parkinson's associations that collaborated with the project.

Methods. Presentation by video-conference of the different mock-ups or in person by visiting the PwP at home. This choice was made by the PwP.

Results. 16 PwP were interviewed (of which 6 participated in the previous interview, and 3 were previously represented by their relatives, but took part in this phase with a face-to-face interview). The results are as follows:

- the screen presented in landscape (75%);
- the buttons aligned horizontally at the top (63%);
- the use of pictograms followed by word(s) for the proposals to complete the text (50%);
- the thumb for the indication of *OFF* period (44%);
- the swiftkey keyboard (81%);



Pictogram only

Text only

Pictogram and text

Fig. 8. Mock-ups for text completion choices

3.5 Evaluate Against the Requirements

The activities *Design and develop solutions to meet the requirements* and *Evaluate against the requirements* were performed twice in an iterative way, represented by the green dashed arrow in Figure 2. In the first iteration, a first version of the software was developed based on the previously defined and validated mock-ups. Next, a first evaluation was carried out. Based on the results of this evaluation a second version was developed and then evaluated by the PwP. Therefore, two evaluation studies were carried out. Ethical approval for these studies was obtained from the ethical committees of Lille University (France) and Mons University (Belgium) under the respective references 2021-548-S100 and 10062022EB.

Both studies essentially followed the same research protocol, differing only in the number of participants and the instrument being evaluated (each produced version).

Goal. The aim of this study was to evaluate the usability perceived by end users of the communication aid software developed on the basis of the needs identified with PwP and their relatives. The environment (in the context of use) for both studies was in the PwP's home. This was defined to guarantee an evaluation in the context of use that was established as most desirable by the PwP as presented in previous section. In addition, we considered inappropriate to subject PwP to carry out controlled evaluation sessions. Therefore, we planned to leave the PwP to use the application to their convenience over a certain time period (minimum 1 week).

Participants. The recruitment method was based on voluntary participation: invitation of the PwP that participated in the previous studies, issuing calls for participation on the Internet and social networks, and contacting Parkinson's associations and hospitals that collaborated with the project. The inclusion criterion was any participant who has been diagnosed with PD, even though the focus of the development was made for a group of PwP at evolving profile level 3 (i.e., those with severe communication problems or who no longer speak), from previous interviews, since the vast majority (11/14) requested the need of the developed functionalities (see Table 2).

Methods. The procedure for carrying out the evaluation consisted of four main phases:

i. *On-site presentation of the software version* - A first meeting took place to explain the functionalities of the software, demonstrate it and also provide brief training for its use. Once the information about the software had been clarified, an agreement to take part in the study was required by signing a consent form;
ii. *Profile data collection* - In the same meeting, we collected information on the PwP, regarding age, gender, years since PD diagnosis, and a self-assessment of their difficulty to talk, memory, and level of tremor in the upper limbs (defined based on [71]). To collect this data, we drew up a paper questionnaire which the researcher used to collect the information and filled in as the interview took place;
iii. *Use of the software application* - The participants were left with a tablet and a detailed user guide of the tool, that was also clearly explained, for a minimum of one week. This period could be extended by user's request. During this time, they were asked to use the software application as an aid to their daily lives. In order to achieve this objective, we prepared a document containing a set of ten scenarios, with a step-by-step explanation of how to perform each one. Furthermore, we established a daily agenda, outlining the minimum number of scenarios to be executed on a daily basis. The ten scenarios are as follows: (1) prepare a text using pictograms; (2) prepare a text and use the vocal synthesizer to communicate with someone; (3) prepare a text, register it and later open it to be used for communication; (4) prepare a text using a predetermined one from the library; (5) modify an existing dialogue and register it; (6) execute an existing text from the library using the synthesizer; (7) perform an urgent request; (8) ask for help; (9) play a piece of music; (10) play a joke. The last two were included as relaxation option.
iv. *Feedback* - A second meeting took place to obtain user feedback on the application, suggestions of improvements, filling out the CSUQ (*Computer System Usability Questionnaire*) questionnaire [45]. To that end, the CSUQ questionnaire was printed, and for each item, users were invited to provide comments regarding their answer. These comments were then written down for further analysis.

Therefore, two visits were made to the PwP's house (one at the beginning and one at the end) in each evaluation. A pre-test was carried out in each evaluation.

Results. For the first evaluation, 18 volunteers (PwP) accepted to participate; 2 of them had already participated in a pre-test evaluation; 4 others abandoned the study for medical reasons, but had started using the application (one of them, for instance, sent a report with some suggestions later). Therefore, 12 volunteers (PwP) did the complete evaluation for our analysis (of which 7 had already participated for at least one of the previous studies).

For the second evaluation, 31 volunteers (PwP) accepted to participate; 2 of them had already participated in the pre-test evaluation (of which one had not yet participated in any previous studies), and two others dropped out of the study. Therefore, 27 PwP fully completed the evaluation (of which 12 had already participated for at least one of the previous studies, and 7 of these 12 in the first evaluation).

Table 4 presents the CSUQ final scores considering the evaluation of all participants in both evaluations. Figure 12 shows that the second version obtained a better evaluation for all CSUQ scores, except for the interface quality that remained almost identical. PwP's main criticism of the first version was the use of the native Swiftkey keyboard. The letters were considered too small and too close together. Including accents was very difficult and, for some PwP, impossible. Some PwP also proposed using an ABCD keyboard instead of the AZERTY (the standard keyboard in the countries where the study was carried out). Another point is that the tablet is very sensitive; for people presenting tremor, it was possible to tap a key twice without meaning to. They suggested introducing, for example, a delay between clicks to avoid typing the same letter twice. Finally, although in the interviews (see Section 3.4) the option for proposition of text completion was to present a pictogram followed by text, they did not like the use of pictograms and asked to use text only.

Figures 9 and 10 show the main screen of the functionality to write a text to support communication of the first and second versions, respectively, where one can note the difference of the keyboard in both versions. A specific keyboard was designed for PwP in the second version, with more separated keys, keys already including accents, and two keyboard types, ABCD and AZERTY. In the second version, the keyboard could be personalised in terms of ABCD/AZERTY options, size of the letters and of the keys. The application screenshot presented in the Figures 9 and 10 have been modified to present the ParkinsonCom application in English. The currently available application languages are French (France and Belgium) and Dutch (Belgium).

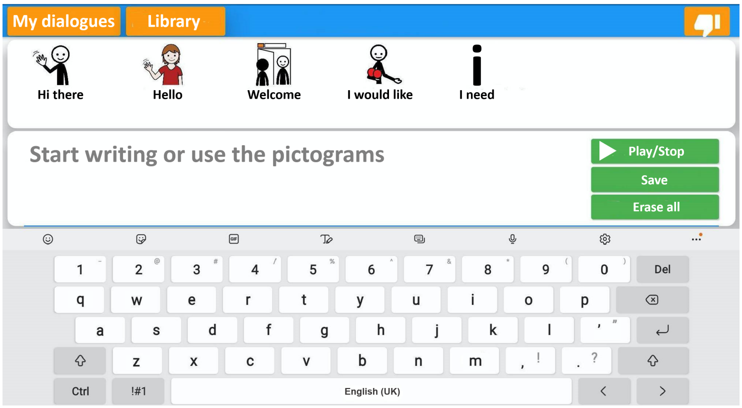


Fig. 9. Main screen for preparing a dialog - 1st version

As presented previously, we accepted all volunteers for the evaluation. To better analyse the results considering only the target population for these versions (PwP in level 3 of the evolving profile for communication), we also analysed the data only of PwP with serious communication problems. To achieve this, we clustered participants based on their self assessment on difficulty to talk (greater or equal to 80%) from the Parkinson's Well-Being Map. Table 5 presents this result. We note that in the first evaluation only 2 participants were in the target group. Unfortunately, the 4 participants that abandoned the study for medical reasons were in the target group. Even with this small number, both PwP contributed proposing several suggestions. We note also that, with the exception of the evaluation of interface quality, all other CSUQ scores had a high standard deviation. One of the participants had strong upper limb tremors, which made the use of the keyboard very difficult, and may affect her evaluation. In any case, the keyboard was not considered adequate for the majority of the users in the first version, which justified the design of a specific keyboard for the second version. Figure 13 shows that when analysing the PwP in level 3 (target population for the developed version), the second version obtained a better evaluation score for all items.

A last suggestion from users was to make the "clear text" option more evident and not in the keyboard, since this option (red dustbin button) was very close to the validation (OK) button (see

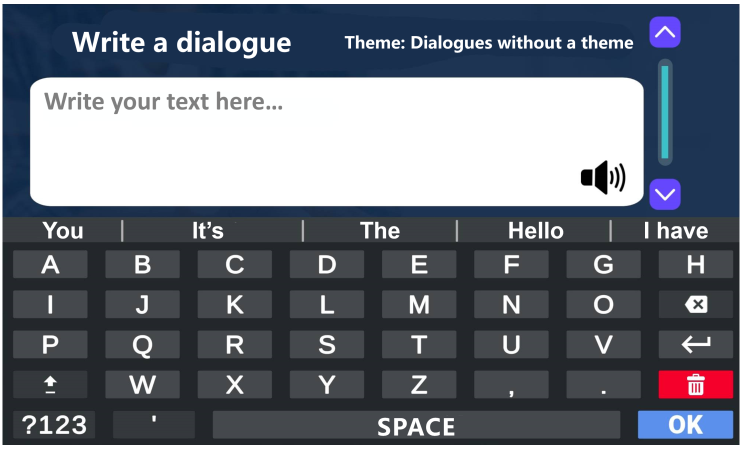


Fig. 10. Main screen for preparing a dialog - 2nd version

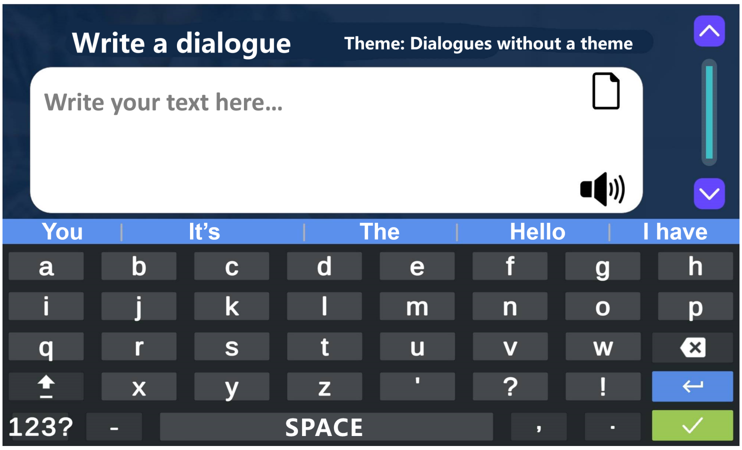


Fig. 11. Main screen for preparing a dialog - 3rd version

Table 4. General CSUQ scores

CSUQ Score	1st Evaluation (n=12)		2nd Evaluation (n=27)	
	Average	Std.	Average	Std.
Overall (Usability satisfaction)	5.29	1.30	5.60	1.12
System usefulness	5.36	1.50	5.54	1.49
Information Quality	5.19	1.36	5.75	1.01
Interface Quality	5.67	1.01	5.64	0.97

red and blue buttons in Figure 10. Figure 11 presents the screen for writing a text for dialogue from the latest version of the application. We note that the ”clear text” option was included as a new page icon inside the text frame.

Table 5. CSUQ scores - User profile level 3

CSUQ Score	**1st Evaluation (n=2)**		**2nd Evaluation (n=7)**	
	Average	**Std.**	**Average**	**Std.**
Overall (Usability satisfaction)	3.58	2.11	5.71	0.62
System usefulness	3.31	2.31	5.77	1.07
Information Quality	3.47	2.13	5.88	0.49
Interface Quality	5.00	1.00	5.71	0.90

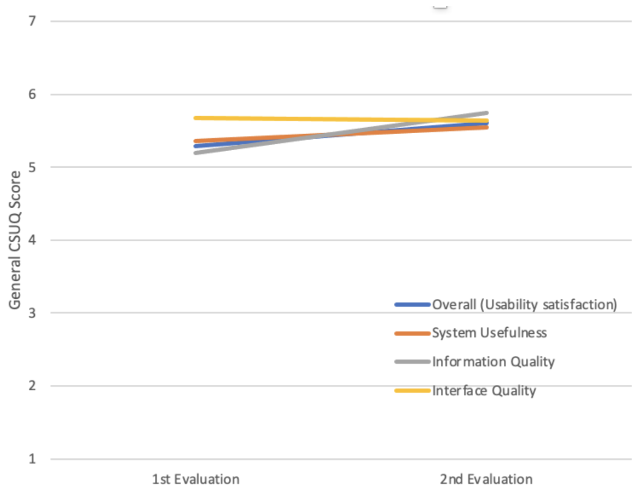


Fig. 12. General CSUQ comparison

Fig. 13. Specific CSUQ comparison

3.6 Threats to validity

A fundamental issue related to conducting experiments is the validity of the results. Therefore, to analyse the results of our studies, we considered the four threats of validity proposed by Wohlin et al. [81]: construct validity, internal validity, conclusion validity, and risk to external validity.

Threats to *construct validity* refer to the extent to which the experimental setting actually reflects the construct under study. We mitigated this threat through different actions. For the survey, although we elaborated the questionnaire using closed questions, we included an open item (”others”), to allow the respondent to include other elements, and also evaluate them. Moreover, the questionnaire was reviewed by a physician expert in PD. For the evaluation of prototypes we used a well-known questionnaire with high reliability (CSUQ), and for each answer the respondent was free to explain and make free comments. The first interview was guided by very open questions, which allowed the interviewees to freely express their opinions. Finally, for the second one, we proposed different mock-ups to each item to be investigated.

Threats to *internal validity* draw from influences that can affect the independent variables with respect to causality without the researchers‘ knowledge. Based on [81], we considered that the factors potentially impacting the studies are related to the selection of participants and their division into different classes and potential special events occurring during the experiment. We did not restrict the selection of participants (PwP) in any one of the study; meaning that we accepted all volunteers that had a diagnosis in PD. However, in the first interview, 4 out of 14 interviewees were the relatives (husband or wife) who answered for their spouse (PwP) due to the latter having strong communication difficulties. Even if the questions were asked with the wording referring to their spouse, a bias may have been present. However, since our goal was to identify the different needs and difficulties regarding communication, we considered that this bias would not affect the result. Therefore, we accepted this threat.

Threats to *conclusion validity* and *external validity* are interrelated. The first concerns issues that affect the ability to draw the correct conclusion about the relationships between the treatment and the outcome of an experiment. Threats to external validity, on the other hand, are conditions that limit our ability to generalise the results of the study to other populations. There is always heterogeneity in a study group. If the group is too heterogeneous, there is a risk that the variation due to individual differences will be greater than that due to the treatment. Choosing more homogeneous groups, on the other hand, will affect external validity. For all studies, we did not restrict the choice of participants (PwP). In the first three studies (survey and interviews), this gave us a broader view of a PwP’s communication difficulties and needs. We therefore feel that we have minimised the risk of external validity. However, we clearly identified a divergence of needs, perhaps affecting conclusion validity. As our goal was to identify this divergence, we accept this threat. For the last study (software application evaluation), we believe that heterogeneity may affect the conclusion validity of the version developed only for the evolving profile level 3. However, we understand that all participants are aware of the evolution of PD and therefore the degenerative evolution of their profile. Therefore, we preferred to assume this threat. In any case, we also analysed the results considering only the target population answers, even though the number is small.

4 DISCUSSION

In this section we present a discussion of the implementation of the ISO process for the context of Parkinson’s evolving profiling, seeking to identify lessons learned (Section 4.1). We write these lessons as recommendations in order to define a first version of a human-centred design process presented in Section 4.2.

4.1 Lessons Learned

Section 3 described a case study using the adaption of ISO 9241-210 standard process to take into account the evolving profile of PwP in the degradation of their communication capacity. The entire process for developing the communication software aid for PwP took almost three years (from April 2020 to December 2022). During this period, 97 PwP, caregivers (the majority, 4 of 5, PwP's relatives) and health professionals participated in the process taking decisions and giving feedback on the propositions. Table 6 presents the number of participants in each activity. It may appear somewhat unconventional that the user is not involved in the specification phase. This is because the needs were defined based on the transcript of the interviews carried out in the previous activity and no conflicts were detected (as explained in Section 3.2.2). In this activity, the other stakeholders were responsible only for determining the most pertinent needs for each level of the evolving profile.

As we adapted each activity of the standard process to address the evolving profile issues, we noted several important issues. Firstly, defining the different levels of the evolving profile is not straightforward. At the start of this project, we expected that we would be able to identify the different levels by combining the results of a set of typical symptoms. However, with the results of the survey and the interviews, we realised that the evolution of the profile is not similar for all PwP, taking into account their symptoms. This was also confirmed by the physicians working in the project. For this reason, with the support of the physicians, we decided to focus on the self-assessment of PwP in relation to their communication difficulties considering the answer of related items of the Well-being Map questionnaire (that was defined for PwP's own use, see Section 2.2). Second, to better perform human studies with the different stakeholders, we should apply various data collection techniques, such as focus groups and co-design with the end users. However, most of the time of this project was during the COVID-19 pandemic, when these activities could not be carried out. We recall that most PwP are elderly, and considered at risk. We were only able to contact them face to face more than a year after the beginning of the process, taking the necessary precautions and having the whole team vaccinated. Third, with a small technical team and due to the complexity of the potential solutions, we could not address all three levels in parallel as proposed. Then, once we had decided to focus on the third level, we hoped to have more volunteers in the test phase at the target level. In addition, the people identified in this level dropped out of the study due to health problems (unrelated to the project). We also realized that with a degenerative disease profile, the volunteers were evolving during the project period. Users who were classified as level 3 at the start of the project often progressed to other symptoms or diseases, and abandoned the study. Some of them passed away. Others who were classified as level 2 ended the project with great communication difficulties or even being unable to speak. We also noticed that some of those who communicated normally at the beginning lost their ability to communicate by the end.

Despite this, this case study provided a real and complete experience of using the proposed process, bringing with it a number of lessons learned. Some of them were also observed by other studies (e.g. [6, 20, 40, 44, 72, 73]). Based on that, we define a set of recommendations for future projects dealing with the evolving profile of users, as presented below:

I. Start large - try to understand the problem you wish to address at the beginning with a large perspective to better understand the focus of your project. For the initial study (Section 3.2, instead of collecting the opinions of PwP from the project's association partners, an internet survey was carried out, which collected responses from 56 disabled PwP from various geographical locations. At the beginning of the project, we envisioned another type of software system, maybe using cutting-edge technologies. The results of the survey showed

Table 6. Human-centred design in numbers

Activity	**Study**	**#PwP**	**#Health professionals**	**#Caregivers**
Understand and specify context of use	Initial interview		**2**	
	Survey	**56**		
	Structured interview	**10**		**4**
Specify the user requirements	Interview		3 **(2 new)**	**1**
Design and develop solutions to meet the requirements	Interview	16 **(10 new)**		
Evaluate against the requirements	1st version evaluation	18 (2 pre-test, **5 new**, 4 abandonments)		
	2nd version evaluation	31 (2 pre-test, **16 new**, 2 abandonments)	1	
Total		97	5	5

that we should keep it as simple as possible. The use of a new technology is not trivial when living with a degenerative disease.

II. Include the target population in the process as much as possible - for sure there is no better expert of a specific degenerative disease than those affected by it. We quickly realized that creating a communication aid software without discussing the everyday experience of a PwP would not work. Collecting future-user feedback on the systems's features was seen as precious advice. The co-construction should also be continuous throughout the process to ensure that the adaptations made to the software are in line with what was requested by the target population. As presented in Table 6, 97 PwP participated of the whole process, all of them declare have some difficulty of communication.

III. Be prepared for users' evolving difficulties during the development process - In a project lasting several years, the intensity of symptoms linked to a degenerative disease can increase significantly. This can lead to impaired communication and/or concentration of the people with evolving profile. We need to be prepared for the fact that participants who started out at the beginning of the project may find it increasingly difficult, despite their motivation, to contribute as the project progresses, due to their illness. Some may even find it necessary to withdraw from the project (e.g., 6 abandoned the final evaluation study, Table 6), for reasons beyond their control.

IV. Accept all volunteers - even if it was important to target specific future users to address our study goals, suggestions and feedback can come from all participants, some of whom would have been missed if we have only focused on our target. We note that of the 39 PwPs (12 in the first evaluation and 27 in the second) only 9 (23%, 2 in the first evaluation and 7 in the second) concern evolving profile level 3. However, several suggestions for improving the application in the evaluation phases came from the other 30 PwP who clearly stated that they evaluated the system taking into account what they know about how they will be in the near future and want to prepare for their future, knowing that their condition will deteriorate.

V. Use on-site evaluation as much as possible - doing the evaluation on-site, in the environment where future users will use the application, and allowing users to use the software when they want to and feel able to, meant that a natural interest in the project and in the use of the software application developed. All 49 evaluations were carried out at the client's home, at a time that was convenient for them. We are convinced that had we opted for a fixed and controlled approach, the results would have been insufficient and we may not have had that number of volunteers.

VI. Repeat the evaluation process - the development of the ParkinsonCom software application was based upon input from repeated evaluations from the future users as recommended by ISO 9241-210. A single evaluation would not have sufficed to achieve the finished product. In some cases, the volunteers tested the product three times and were continuously suggesting improvements. We have performed two iterations only for level 3. To test the whole application addressing all levels, several iterations would be necessary.

VII. Know when to stop - given the nature of an evolving profile and the size of certain disease spectra, such as PD, it may be tempting to fall into the trap of wanting to please everybody. However, constantly adding new features renders software applications more complex for the users and demands higher computational time. This may run the risk of decreased usage and appreciation due to increased complexity. In this case, clearly identify the main needs for each level of the evolving profile. In our experience, as users engaged with the application, they expressed a need for additional functionality that wasn't necessarily focused on communication issues (for example, an agenda to remind them when to take their medication). We began to respond to these needs in order to encourage user interest in the final application. At a certain point it was necessary to stop responding to new requests and focus on the next levels of the evolving user profile.

4.2 Towards a Human-centred Design of Interactive Systems for Users with Evolving Profile

Considering the preceding lessons learned and the observation that the evolving profile is a hallmark of any degenerative disease, we formulate a preliminary version of a human-centred design process when users have an evolving profile presented in Figure 14. In this process, the various recommendations presented in the preceding section were integrated. The implementation of this process can be further developed in other projects and improved if deemed necessary. Each activity was reviewed considering the perspective of developing an interactive system for users with an evolving profile, as described below.

Plan the human-centred process. In this activity we should describe the activities to be performed, the material and human resources, cost and time constraints. In the case of developing an interactive system for users with an evolving profile, each of these elements must be carefully analysed. As far as human resources are concerned, in addition to technical HCI designers and programmers who are experts in the technology to be used, it is necessary to identify the necessary stakeholders (e.g. physicians, health professionals, caregivers, family members and friends), who are important in helping to understand the users' evolving profile in relation to the problem we want to solve. We must seek out these stakeholders beforehand and make sure they can participate in the whole process. According to [11], in order to distinguish the different types of participants, it

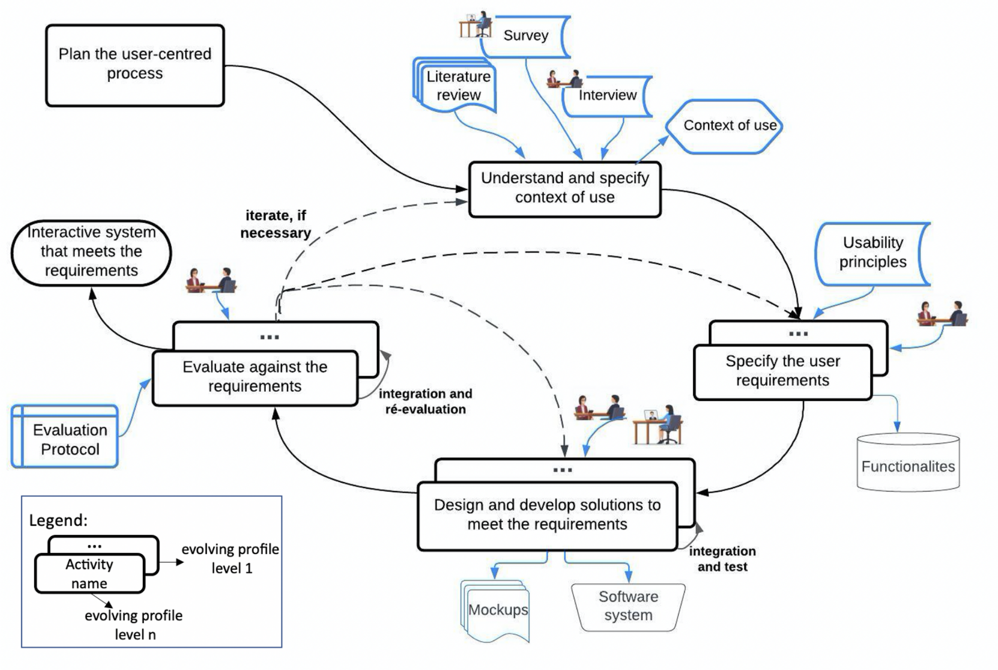


Fig. 14. ISO 9241.210 standard [38] adapted for the design of interactive system centred on users with an evolving profile - the overlapping of activities means their execution for each level of the evolving profile

is important to specify decision-making situations and the groups of participants, communicating who can participate in decisions, with what rights, at what time and on what subject. In addition, we must analyse their constraints in terms of time and local availability to participate. The technology that will be used to solve the problem must also be conscientiously researched in order to best meet the users' needs (be aware that the most modern technologies are not always the most suitable).

Understand and specify context of use. Given the need to develop an interactive system for an evolving profile, this activity should start with a literature review to properly define the problem and understand the disease we will be working with. With a basic knowledge of the subject, one or more interviews with physicians and/or health professionals identified in the previous activity should be carried out. The aim is to confirm understandings obtained from the literature, discuss the difficulties faced by people with an evolving profile and, if possible, potentially ask about the different levels of the evolving profile that could be established. A first identification of potential technology to be used or discarded can also be envisaged. Only after that, we can start to investigate the user needs. In participatory research [11], the mobilised community member has a significant degree of involvement in the project definition process. Based on that, we propose to use a wide-ranging study method such as surveys in order to identify the user profile with their variability taking into account the evolution of the disease and the focus of the system in question. The idea is to have a general view of the disease in terms of symptoms' impact in daily life, difficulties and needs regarding the problem to be addressed. Interviews can also be applied in a complementary way. These can be carried out with the potential future users, but also their entourage (including caregivers, relatives, friends and medical professionals previously identified) so to gain a deeper and clearer insight into the usability needs linked to the disease. The aim is to identify the different levels of disease progression concerning the problem to be addressed that can be characterised by the user's personal characteristics. These different levels may impact the definition of different contexts of system use and may also require different technological solutions.

Specify the user requirements. This activity should be started with one or several structured interviews with the physicians and/or health professionals, in order to present the results obtained in the previous activity, the propositions of evolving profile levels and possible solutions for the envisaged problem. In the event of conflict being detected, it is recommended that new interviews be carried out with user and techniques for managing conflict be applied [65]. The goal in this activity is to validate with the physicians and/or health professionals the propositions in terms of feasibility for the users with the specific evolving profile. In this/these interview(s), discussions about the different functionalities to support the users in each level of the evolving profile can enrich the proposed solutions with new insights from the experience of the physicians and health professionals with the target problem. For each identified level of the evolving profile, the users may have different needs, leading to different functionalities/requirements, which can be considered as different applications within the same software. Figure 14 shows this fact by the drawing of this activity repeated in an overlapping manner. Other interviews can be carried out if necessary to define the functionalities for each level. Considering all the collected data from the survey and interviews, several personas [55] can be written to better specify the needs of the users focusing in the different needs of each level of the evolving profile.

Design and develop solutions to meet the requirements. For each proposed specification of a evolving profile level, a design and development of the requirements should be produced. The overlapping of several rectangles in Figure 14 represents the design for each specification produced in the previous activity. This activity requires end users to think through and conceptualize all their ideas as individuals and collectively; they can be accompanied by their family or professional caregivers. The goal is retaining what best corresponds to their needs in terms of user interface design. In this way, participatory design or co-design approaches [67] can be used to actively integrate all the stakeholders, and mainly, the potential end users. In this activity, it is strongly recommended to define and/or validate mock-ups with the users. To achieve this, focus groups or individual interviews with users and stakeholders (caregivers, friends, family, health professionals) may be applied. Depending on whether or not the software development is carried out in parallel to meet the specific needs for each level in the evolving profile, integration and testing of the different components that address each level must be carried out continuously while developing the specific functionalities to address the requirements.

Evaluate against the requirements. Once a version of the system is produced, human-computer studies should be carried out with users. Application of usability tests are recommended. Considering the evolving profile, there is a risk that users who participated in the previous activities do not have the same needs since their profile evolved in a degenerative way. We should therefore include new users for evaluating the systems who did not participate in the requirements and design phase. Being aware of that, the evaluation studies in this phase should consider the presentation of the project and the interactive systems being developed. Another aspect to consider is that it can be not easy to submit users to controlled usability-test sessions. In this way, evaluation protocols must take into account the nature of evolving profiles and plan feasible evaluations at a convenient time and in a manner agreed with users. This research protocol should be formally described and approved by ethical committees before performing the evaluation. Considering the different levels of the evolving profile, one or several evaluations should be done for each level (also represented by the overlapping of rectangles in this activity in Figure 14). Several evaluations are carried out when the results show the need to iterate by doing/improving the design and implementation or by refining the specification (see dashed arrows in Figure 14). It is recommended to use at least one usability questionnaire (see [7] for a review on different standard usability questionnaires) in other to collect the feedback and measure the usability satisfaction. Similar to the previous activity, if the evaluation was done in parallel to meet the specific needs for each level in the evolving profile, the integration and re-valuation of the different versions of the system should be performed.

5 CONCLUSION

This article has presented a case study of the definition and application of a human-centred process for the development of interactive systems for people with Parkinson's disease, i.e. users have an evolving profile. This process is supported by a set of user studies carried out from a broadest to most specifics, focused on an identified user profile level. It has taken a step forward by presenting a first version of a generalised software process for the development of software systems when users have an evolving profile.

This article contributes to academia by taking a particular look at the generic process of the ISO 9241-210 standard for the situation when dealing with users with an evolving profile (e.g Parkinson, Alzheimer). In addition, it contributes to practice as it shows step by step how this process was applied in a real case of a large project. Ninety seven (97) people with Parkinson's disease, 5 health professionals (including a physician expert in PD, neurologists and speech therapists) and 5 caregivers (mostly family members) took part in the human-centred design, implementation and validation of ParkinsonCom software application for level 3. In addition, 111 site visits were carried out by the project team (after December 2021) to ensure that the software developed met the needs identified by the target audience as closely as possible. In addition, 165 PwPs have been trained and the ParkinsonCom software has been presented to a thousand people at various scientific, medical and general public events. ParkinsonCom is available on the project's website (https://parkinsoncom.eu) for free download (currently totalling 1,852 downloads[5]).

In future work, we plan to extend the ParkinsonCom software application, to address level 2 of the evolving profile, by proposing functionalities that could capture PwP's voice while speaking and proposing words in real time to complete the sentences when they are blocked due to forgotten words. This involves the use of advanced artificial intelligence algorithms and precise devices for voice detection.

Furthermore, this experience highlighted the importance of defining profile levels at the outset of the process. It is clear that a significant amount of future work is required to define a generic method for specifying evolving profile levels and all the associated attributes that would be useful for characterising each level.

Acknowledgments

The ParkinsonCom project was developed with the support of the Fonds Européen de Développement Régional Interreg V France-Wallonie-Vlaanderen and the Agence pour une Vie de Qualité (AVIQ), Belgium, to whom the authors would like to express their gratitude. The authors would like to thank all the participants involved in the various phases of the project and the three Parkinson's association - FranceParkinson Nord (France), Vlamseen Parkinson Liga and Association Parinson APk, asbl (Belgium) - without whom this work would not be possible.

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[5] last access on April 24, 2025

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